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Abstract

Objective

Young people with chronic illnesses, such as epilepsy, tend to have poorer psychosocial outcomes compared to their peers. Nevertheless, not all young people experience difficulties adapting to living with epilepsy. The aim of this study was to examine family processes, as little is known about their impact on young people's adaptation to the condition.

Method

Semi-structured interviews were conducted with 15 young people, aged between 13 to 16 years old, to explore their experiences of living with epilepsy from the perspective of family resilience.

Results

Findings from these interviews provided in-depth descriptions of stressful circumstances encountered and family processes. These processes, which in turn promoted positive adaptation, included shared family beliefs, family connectedness, and communication processes that supported collaborative problem-solving.

Conclusion

Practitioners who support young people living with chronic conditions, such as epilepsy, should consider interventions that promote family connectedness, as it allows young people to turn to their families for support in times of stress. Additionally, it is important to explore young people's beliefs, helping them and their families construct a new sense of normality if necessary. Supporting open communication between family members, where differing views were acknowledged, is likely to be important in facilitating resilience.

Keywords: Adolescents; Epilepsy; Family resilience; Chronic illness; Qualitative

Young people's experiences of living with epilepsy: the significance of family resilience

Young people with epilepsy tend to have poorer psychosocial outcomes compared to their peers: this includes higher levels of behavioral problems, lower quality-of-life and social competencies, and poorer academic achievements (Plioplys, Dunn, & Caplan, 2007; Rodenburg, Wagner, Austin, Kerr, & Dunn, 2011). However, the impact of a chronic illness is not restricted to individuals but also extends to their families. Living with a family member with epilepsy is challenging, placing additional stress and burden on families in coping with the unpredictable occurrence of seizures, seizure severity, and complexities of medical treatment (Smith et al., 2014). Families of young people with epilepsy report poorer parent-child relationships, greater problems with family functioning, higher levels of stress and conflict, compared to families in comparison groups (Rodenburg, Meijer, Dekovic, & Aldenkamp, 2005). These difficulties with family functioning predict poorer adaptation in a range of psychosocial outcomes in young people (McCusker, Kennedy, Anderson, Hicks, & Hanrahan, 2002; Rodenburg et al., 2005).

Despite the challenges of living with epilepsy and higher risk of negative outcomes, some young people are successful in managing additional demands and do not necessarily experience poorer outcomes (Baki et al., 2004; Chiou & Hsieh, 2008). They are often described as resilient. Resilience is often referred to as an individual's capacity to recover from, adapt or remain strong in the face of adversity. In other words, resilience describes individuals who (i) have good outcomes despite being considered high-risk for maladjustment (e.g., chronic medical condition), (ii) maintain competence despite threats to their well-being, or (iii) recover from trauma (Masten & Monn, 2015).

In previous literature, positive adaptation was often defined as either successfully achieving age-appropriate development tasks or the absence of behavioural and emotional problems (Luthar, Cicchetti, & Becker, 2000). Shifting toward a strengths perspective, evaluations of adaptation were extended to include assessments of young people's self-esteem, social competencies and functioning, academic achievements and quality of life (Barakat, 2008). In his seminal paper regarding psychosocial resilience, Rutter (1987) emphasized and elaborated on four protective mechanisms that explain individual variations in young people's responses to risk and adversity. One of which was, *establishing and maintenance of self-esteem and self-efficacy* in the face of adversity (Rutter, 1987). This process is particularly crucial at major developmental transition points, such as adolescence, as risk trajectories may be redirected onto a more adaptive path (Rutter, 1987). Thus, self-esteem – the

value that an individual places on his or herself – is an important indicator for resilience. The role of self-esteem in young people's development has been well documented and widely used as an index for an individual's overall psychosocial functioning. However, the effects of epilepsy and mediating processes that promote or maintain young people's self-esteem in relation to the added demands of living with epilepsy, is less established (Chew, Haase, & Carpenter, 2017b).

A wide range of protective factors has been hypothesized to foster resilience. The availability of external resources, such as parental and family support, positive peer relationships and mentoring programs organized by community organizations, reduce the likelihood of poor outcomes among high-risk youth (Pinkerton & Dolan, 2007; Zimmerman et al., 2013). These protective factors shape young people's strategies in managing stressful demands that arise from adversity and mitigate against poor outcomes such as low self-esteem (Boyden & Mann, 2005).

At present, there is a limited number of studies that examined family influences on psychosocial outcomes of young people with epilepsy, and very little that explores family processes from their own perspectives. Among quantitative studies that investigated relationships between family factors and psychosocial outcomes, most used parental reports to measure family functioning. Results from these studies document significant associations between family functioning and a range of psychosocial and health outcomes (Rodenburg et al., 2005). Difficulties with family functioning predict poorer psychosocial outcomes in young people, such as higher levels of behavioral problems, lower self-esteem, lower social competencies, and poorer academic achievement (McCusker et al., 2002; Rodenburg et al., 2005). Qualitative studies, which engaged young people as active respondents, primarily focused on their descriptions of living with epilepsy with limited information on family processes such as communication and cohesion (Chew, Carpenter, & Haase, 2017a). On the whole, the views of young people living with chronic conditions about family processes are lacking (Carpenter & McConkey, 2012).

As highlighted, the notion that the mere presence of a chronic medical condition is inadequate in explaining young people's risk for poorer outcomes: differences in outcomes were accounted by other factors, such as family factors that promote resilience. One approach to understanding these variations is using a family resilience framework to explore processes that support young people's positive adaptation. Walsh's (2016) family resilience framework considers families as a resource that individuals may harness in order to cope with adversity, such as living with a chronic medical

condition. Key family processes that foster resilience occur in three primary domains of family functioning, namely, family's belief systems, organizational patterns, and communication and problem-solving processes (Walsh, 2016). These processes do not occur in isolation. For example, family members' ability to communicate well with each other is likely to facilitate collaborative problem-solving. Conversations regarding young people's frustrations about missing out on social activities due to their seizures may result in novel solutions (e.g., parents taking proactive steps to educate friends in ways to manage and respond to a seizure episode). Such cooperation and communication will likely reduce feelings of exclusion and mediate the impact of epilepsy on young people's self-esteem. Walsh's resilience framework provides a basis from which one can examine the interplay of family-related variables that affect young people's psychosocial functioning.

Therefore the focus of this study was to use a family resilience framework to explore young people's experiences of living with epilepsy. In particular, key family processes that facilitate self-esteem – an indicator of adaptation and resilience – will be examined as such knowledge will be valuable to social workers and other professionals in supporting these young people and their families.

METHODS

This study was part of a larger project that examined young people's experiences of living with epilepsy: semi-structured interviews with young people formed this second strand of a sequential mixed-methods research design. Findings from the first part of the project – a quantitative survey administered in a hospital clinic – are reported elsewhere (Chew et al., 2017b). Between November 2013 and August 2014, 176 young people who met the following criteria: (i) diagnosed with epilepsy, (ii) aged between 13 and 16 years old, and (iii) attending mainstream school, were recruited from the pediatric neurology services in KK Women's and Children's Hospital. SingHealth Institutional Review Board approved this study.

Characteristics of Participants

Of the 152 young people who participated in the initial survey, 31 agreed to be contacted again for interviews. Parents were first approached by telephone to obtain consent to get in touch with their child as it would have been inappropriate to contact young people without first seeking their parents' permission. Sixteen parents declined stating that their child would be too busy, would not have much to say or that they were not interested. Fifteen parents consented to further contact and all the

children concerned agreed to be interviewed. Ten young people were Chinese and five Malay (the proportions in the general population are around 75 per cent and 15 per cent respectively) (Table 1). Their scores on the Rosenberg Self-esteem Scale (RSS) and Family Resilience Assessment Scale (FRAS), taken from the initial survey are also included. Of which, nine had lower self-esteem scores ($n=152$, $Mean=28.78$, $Standard\ deviation=6.04$), and eight had lower family resilience scores ($Mean=155.48$, $Standard\ deviation=24.83$), compared to the overall sample mean. For both scales, higher scores were indicative of higher levels of global self-esteem and family resilience.

Data Collection Procedures

Young people determined the time and location for their interviews: all but one were conducted in their homes. They were informed that their views would be kept confidential, even from their parents, unless information regarding abuse or harm was revealed. Written consent for participation was obtained from both young people and their parents. Digital audio recording was requested from all but one participant who was uncomfortable with recording. Semi-structured interviews explored their experiences of living with epilepsy and of how individual and family factors might have influenced their adaptation to the condition. The interview guide was developed to reflect this objective. Some of the topics were: (i) living with epilepsy (e.g., *'Can you tell me what it like is to have epilepsy?'*), (ii) relationships with family and friends (e.g., *'How do you feel it has affected your relationships with your family, your friends, and interactions in school?'*), and (iii) family processes (*'Who do you talk to in your family if you had any problems?'*). Circular questions, which are often used to explore family processes and interconnectedness within families (Tomm, 1988), were interwoven with the interviews (e.g., *'How will your family respond to what you've just said?'*, *'Who in your family will agree/disagree with what you've said?'*). Interviews lasted between 42 and 80 minutes, with an average duration of 50 minutes.

Framework Approach to Data Management and Analysis

All interviews, except for one, were audio taped and transcribed verbatim. NVivo 10, a computer assisted qualitative data analysis software, was used to aid with data management and analysis. The analytic approach for this study was guided by 'Framework' analysis (Ritchie & Spencer, 1994). It is considered a form of thematic analysis, an interpretive process where themes describing a phenomenon are described and patterns within the data are identified (Braun & Clarke, 2006). The Framework approach comprises two stages: (i) data management, (ii) abstraction and interpretation.

Although this two-stage approach provided a structure for how data was managed and analyzed, these processes were iterative (Ritchie & Spencer, 1994). The first author carried out the qualitative data analysis. In order to maintain rigor of the analytical processes and increase credibility of the research findings, both second and third authors reviewed the thematic framework and examined whether themes were derived from the data. This process ensured that the final themes remained true to young people's accounts.

Stage 1: Data management. Data management involved identifying themes, sorting and synthesizing the raw data. First, transcripts were read and re-read in order to become familiar with the diversity of circumstances and characteristics within the data: second, to construct the initial thematic framework (Spencer, Ritchie, O'Connor, Morrell, & Ormston, 2014). Walsh's resilience framework, the interview topic guide and findings from a qualitative review of young people's experiences (Chew et al., 2017a), were also used in the development of the initial thematic framework. In constructing a thematic framework, topics were grouped into themes and subthemes that described young people's experiences of epilepsy, including family processes. Third, interview transcripts were indexed according to the thematic framework developed: these themes remained descriptive rather than abstract at this point and were grounded in the original data (Spencer et al., 2014). This process of indexing helped refine and clarify meanings of themes and sub-themes, allowing a more nuanced understanding of young people's narratives. Fourth, themes were refined by reviewing data extracts within each theme and sub-theme. Fifth, matrices where columns represented sub-themes and rows represented individual participants were constructed, and data extracts from each theme were summarized in succession.

Stage 2: Abstraction and interpretation. Building on earlier data management process, elements characterizing young people's responses regarding their experiences of living with epilepsy were identified from summaries within framework matrices. Next, these identified elements were grouped according to underlying dimensions that differentiated young people's experiences. These dimensions were further classified into higher order categories. For instance, single-dimensional typologies were created for some themes where young people's responses could be categorised into groups and when these dimensions could be ordered. An example was family connectedness, which was classified into (i) Weak connections among family members, (ii) At least one strong connection with a family member, (iii) Multiple strong connections with several family members, and (iv) Strong

connections among all family members. Beyond developing categories, which allowed for richer descriptions of young people's experiences of living with epilepsy, possible linkages were searched for between themes. A conceptual view of interconnections between young people's perspectives, attitudes and behaviors were developed in order to understand relationships that could possibly explain variations in their adaptation to living with a chronic condition. These linkages potentially exist between themes (e.g., beliefs and medication adherence) or between sub-groups and themes (e.g., high/low self-esteem and family resilience). An example of identifying linkage between the themes 'Family connectedness' and 'Family support' is presented in Table 2. Lastly, possible explicit and implicit explanations were developed to make sense of themes and patterns in relation to young people's experiences. Explicit and implicit explanations refer to those provided by participants and those inferred from young people's experiences, respectively.

FINDINGS

Prior to discussing family processes, young people discussed a range of challenges of living with epilepsy for both themselves and their families. This included: (a) the physical effects of seizures, including post-seizure effects on their physical wellbeing, (b) the demands of illness management, such as adherence to medication regimens and physician-recommended lifestyle changes, (c) disruptions to their day-to-day functioning, and (d) challenges in achieving positive outcomes in key developmental areas such as peer socialisation, independence and autonomy, and self-esteem. In the area of family process and resilience, three key themes emerged from the analysis: belief systems, organizational patterns and communication processes.

Belief Systems: Meaning Making and Positive Outlook

Family beliefs, such as mastery and control, and normality, influenced young people's responses toward living with epilepsy.

Beliefs about mastery and control. Young people's narratives supported Walsh's argument that a positive outlook, which includes a sense of mastery, promotes resilience (i.e., higher self-esteem). Beliefs about mastery had a strong influence on how young people coped with the demands of living with epilepsy. Often, young people's beliefs about living with epilepsy mirrored that of their parents. For instance, a participant spoke of recognizing and accepting the uncontrollable aspects of epilepsy.

P6: ... *just enjoy life, I can't do anything about it [epilepsy], to change it, so I have to just accept. And since I can't do anything, never mind, just take it... I tell myself, don't need to be bothered about it [restrictions]. I think that is more helpful.*

I: *If your parents were to hear what you have just said, what would they say in response?*

P6: ... *I also think that my dad will agree with me in not letting things prevent me from doing things that I want... He would agree that if it's something you can't do despite your efforts, then don't waste your time. Spend my time on other things that is more fruitful. And that no one can get everything they want in life and that's life.*

A strong sense of mastery was common among young people who had higher self-esteem or those who were less affected by epilepsy-related challenges. In contrast, there was an absence of such beliefs among young people with lower self-esteem. Young people with a sense of mastery regarded 'positivity' as a coping mechanism, emphasizing it was unproductive to dwell upon the negative aspects of living with epilepsy. Instead, they highlighted that it was essential to look forward to good things in life. Positivity was neither a forced sense of optimism nor a disregard of their feelings about actual restrictions and limitations faced. These young people focused on their abilities, accepted that certain aspects of epilepsy were beyond their control, they channeled their efforts toward fulfilling their responsibilities (e.g., adherence to medication) and actively pursued their interests. This in turn reinforced a personal sense of control over their lives.

Beliefs about what is normal. Young people with chronic illness often place great importance on being like their peers. Not only do they strive to be 'normal', they also wanted to be treated likewise (Ferguson & Walker, 2012). Young people's maturity of thought was evident when they spoke of normality. They recognized actual differences when they compared themselves to their peers (e.g., with and without illness, restrictions, etc.). Yet, most did not appraise themselves negatively and expressed that the presence of a difference was not synonymous to being different. Young people elaborated that differences among individuals were '*normal*' and by extension, they too were normal.

Family beliefs played a role in young people's positive views of themselves. Being told they were just like others, and being encouraged to lead a normal life contributed toward their sense of normalcy and confidence in their abilities to carry on with life, respectively. One young person further elaborated that her parents would likely echo her sentiments.

'I think they [parents] will agree with me. Because they also tell me that I must lead a normal life, like others. And sometimes they will say that don't think I have epilepsy and I can get away with things. Like PE (physical education). They also say that everyone is different, but everyone has to do what they have to do. So I have epilepsy, other people may have other things. Everyone will have their strengths and weakness. So, it's like we are different, but also same.' (P14)

There was an interesting exception where a young person (P1) felt 'special' for having epilepsy, despite her frustrations regarding seizures and treatment adherence. While her family members did not share similar levels of optimism, they reportedly affirmed her attitudes.

Not only was the notion of normality instilled through verbal communications, it was intentionally reinforced by not over-emphasizing the impact of epilepsy on day-to-day routines. Some related that epilepsy was not often discussed within their homes because it was part of their lives.

'We don't specifically discuss about it [epilepsy]. My mother will remind me to take medicine and sleep early. But discuss about feelings about epilepsy, not really. It's more matter of fact... It's like we don't talk about whether or not we have to go to school. We just have to go. Happy or not, we have to go to school. So maybe it's like that.' (P3)

Organizational Patterns: Family Connectedness

Most young people described their relationships with family members as 'close' or 'good'.

Correspondingly, these young people described strong relationships among family members. Family connectedness was perceived low in three families as their interactions were often conflictual or distant. Features that characterized strong family connectedness were engagement in shared activities; validation and acceptance of young people's feelings; providing and receiving both emotional and instrumental support in times of need; demonstrating affection and warmth; and successful management of family conflict. Young people from strongly connected families reasoned that shared activities, such as family outings, daily conversations and having meals together, were essential elements that promoted their sense of connectedness as it created opportunities to engage with each other.

'... with my mother, I feel close when we spend time together. With my brother too, but we do different things together. And my father, because he works late sometimes, so even watching TV together when he is home early makes us feel close' (P3)

On the contrary, young people from weaker connected families lacked quality time spent together as a family. Young people and their families sustained connectedness by respecting each other, which included valuing individual opinions, recognizing and accommodating each other's needs.

Family members serve as important sources of emotional and instrumental support, which buffered the effects of stress on young people's well-being. Strong family connectedness is likely to correspond with greater support received in times of need. An example from a participant, illustrates contrasting relationships and support from each parent.

P5: I think it's because we spend time together, we depend on each other and have to be there for each other. Family right, so when there are problems, we have to support each other.

I: Support in what ways?

P5: Like listen to each other, talk to each other, be patient with each other, spend time with each other. And that's why I say [I'm] not so close with my father, 'cos I don't see him so often, so no chance to spend time together to be close, right.

However, despite strong connections with their families, five participants preferred to keep their feelings and concerns to themselves. There were several reasons for this. Some felt that sharing concerns was neither necessary nor beneficial. Others did not want to burden their family members. For instance, one participant's sense of protectiveness over his mother played a role in his decision to withhold information.

'Well, telling people things does not solve anything, does not make sad feelings or bad feelings go away, so just keep to myself. And what if I tell my mother and she also becomes sad? I don't want that to happen.' (P9)

Notwithstanding their reticence about sharing their emotions, these young people would do so when asked. Furthermore, they were confident that their families would be there for them when needed.

This was in contrast to young people from weakly connected families who kept their feelings to themselves. Communication between these family members was infrequent with limited content. Additionally, these participants reported that their family had more arguments compared to their friends and perceived their families to be unlike others. While the lack of conflict is not synonymous with strong family bonds, these participants characterized connectedness as a lack of conflict.

Communication Processes: Collaborative Problem-Solving

Communication within the family was discussed within the context of young people's participation in various leisure and social activities. Most young people engaged in regular social activities with their friends and had similar curfews as their siblings and friends. However, they felt that parents unnecessarily limited the types of activities and time spent with friends. Parental control and overprotectiveness were perceived as barriers to participation, and young people often used strategies, such as bargaining, reasoning, and persuading, to influence their parents' decisions. Two case illustrations are presented next to highlight contrasting features of several family processes that facilitated shared decision-making regarding young people's participation in social and leisure activities with friends.

Case illustration 1: 'My parents came along'. The processes of persuading, negotiating and compromising were particularly salient in a young person's experience. A series of interactions between P12 and her parents illustrate how this family, including her extended family, engaged in collaborative problem-solving to arrive at a solution that was acceptable to everyone. P12 was diagnosed with epilepsy when she was 9 years old and was continuing to experience seizures despite medication. After transferring to secondary school at 13 years old, she wanted to socialize more with her friends as it was the 'common' thing to do. However, her parents did not permit this, which led to a series of arguments. Initially, parental decisions were made unilaterally and her negotiation strategy, attempting to allay parents' fears regarding her safety, was ineffectual.

'I wanted to go out [with my friends] more often, and then initially they kept saying no... And worse, all these places have water. I told my parents I won't be swimming, but they still said no. Then I was angry'

Exclusion from social activities contributed to her feelings of being different, and she started to experience epilepsy as a burden.

'I remember I was angry and sad at the same time. That was when I felt that epilepsy was so troublesome... [It got] more and more frustrating and I started to really hate epilepsy. I used to think it was ok, but when I could not do things because of it, it was not ok. It's like, why is it that my friends can do things and I cannot? Then when they talk about it, or post photos on Instagram, I get jealous that I am not there. Then sometimes I feel left out, like I am an outsider.'

Her parents recognized her wish to be with her friends and offered an alternative (i.e., invite friends to their home). However, P12 rejected this option. Disagreements continued and the family remained at an impasse until an extended family member suggested that parents consider other alternatives that provided P12 with greater independence.

‘... my aunt persuaded my mother to let me go [out with friends]... I don’t know what she actually said, but something like they must let me try and cannot keep me at home all the time.’

Subsequently, the parents proposed a different option, which was to accompany P12 on her outings with friends. Albeit an unconventional alternative, P12 recognized her parent’s concessions and agreed to their proposed arrangements. Thus achieving a compromise.

These interactions highlight processes involved in seeking mutually acceptable solutions. Parents’ proposed solution (i.e., accompanying her) simultaneously addressed their concerns about her safety and increasing preference to socialize with her friends beyond the home environment. When resolving their differences, both parties demonstrated flexibility, openness to trying new solutions and a willingness to compromise and reciprocate. For instance, at various points, both P12 and her parents considered the other party’s needs and were willing to make a compromise. At the systems level, this case illustration also highlights interactions between a family with its extended family and a young person’s social network. Seeking support from extended family members and establishing stronger connections with young people’s networks expanded possibilities in problem-solving. Finally, this family built upon small successes that promoted greater independence in P12, i.e., going out with her friends on her own.

Case illustration 2: ‘No use trying to talk, I won’t get my way’. P15, shared several examples of his unsuccessful attempts to persuade or negotiate with his parents. He was diagnosed with epilepsy when he was 7 years old and would often be physically exhausted after a seizure. Similar to P12, his seizures were not controlled despite medication. Occasionally, P15 recognized his physical limitations and chose to rest at home instead of participating in school activities. However, when he felt sufficiently well, his mother continued to restrict his participation, as she maintained that rest was required. Attempts to convince his mother were often met with a re-assertion of parental authority, e.g., ‘No means no’ or the use of threats. In order to avoid embarrassment, P15 felt that he had no choice but to obey.

‘... if I insist [on going for school activities], she will say, “No use going, I will call your teacher and ask them not to let you do anything.”’

Concerned about his friends’ ability to manage a seizure episode, parents also limited P15’s peer interactions. Despite being aware of his parents’ concerns, P15 felt their methods of ensuring his safety were incommensurate with the risk of harm. But, he was unable to convince them otherwise.

‘They [parents] are worried I have a seizure... how long can they not allow me to go out right? And, at most call the ambulance if something happens. But no use, no use trying to talk to them about it, I won’t get my way.’

Over time, these patterns of interaction reinforced his belief that there was no room for discussion and negotiations were futile. As such, his attitude toward managing disagreements was to maintain silence, e.g., *‘No use arguing, so just keep quiet.’* His parents’ assertion of power has a constraining effect on P15’s attitude toward decision-making and conflict resolution. Resentment and a sense of powerlessness were salient in P15’s narrative. Although P15 and his parents’ positions regarding participation were not extremely polarized, the inability to come to an acceptable compromise strained relationships within the family.

These case illustrations described interaction patterns that facilitated or hindered collaborative problem-solving in the context of differing opinions regarding participation. Given the reality of power differentials within parent-child relationships, particularly within Chinese and Malay families, having the space to negotiate is critical to successful collaborative problem-solving. As reflected in the examples of positive and negative interactions, power differentials may be minimized through parents’ acknowledgement of their child’s needs. The willingness to compromise provided opportunities for both parents and young people to manage their worries and engage in meaningful social interactions with their friends, respectively.

These case illustrations provide further information about inter-relatedness between collaborative problem-solving and family connectedness. Young people’s narratives suggested that those who felt connected with their families were more able to engage in negotiations with their parents. Family members felt valued when decisions accommodated their various needs, in turn, this strengthened their relationships. On the contrary, family connectedness was negatively affected when conflict arose and differences remained unresolved. As seen from P15’s experiences, young people

who avoided conflict tended to distance themselves from their families, which inadvertently affected their sense of family connectedness.

DISCUSSION

One of the aims of this study was to examine processes within families, as little is known about its influence on young people's self-esteem. Findings revealed that although illness-related demands may be challenging, several families demonstrated resilience through their ability to effectively manage the added demands and stress. Family processes that promoted resilience included shared family beliefs, family connectedness, and effective communication that supports collaborative problem-solving. These processes supported young people's efforts in managing illness-related demands and influenced how they viewed themselves.

Family Beliefs

Family belief systems influence how individuals and families make meaning of the illness, guide decisions and actions, and are socially constructed through the interaction with significant others and with other systems (Walsh, 2016). Family beliefs about normality, mastery and control have had a strong influence on how young people viewed themselves and coped with the demands of living with epilepsy. Young people with chronic illnesses often want to be seen as 'normal' (Ferguson & Walker, 2012), and young people in this study were no different. These findings regarding the influence of family beliefs on young people's self-esteem were similar to two studies that described young people's experiences of family support. In these studies, the majority of young people who expressed they were 'normal' and were no different from others had parents who encouraged them not to be limited by their medical condition (MacLeod, 2009).

Young people who had a positive outlook, with a greater sense of mastery and control, demonstrated greater self-confidence and acceptance of their medical condition. Their endeavors to gain mastery was a coping strategy to reduce strains that arose from living with epilepsy. These coping strategies, which were efforts to *adapt* to stress, were more suitable to meet the demands of uncontrollable aspects of chronic illness, as opposed to primary control coping (e.g., problem-solving, emotional modulation) that attempts to *change* the source of stress or reactions to it (Compas, Jaser, Dunn, & Rodriguez, 2012). Furthermore, it is likely that young people sustain or increase their self-esteem whenever they are successful in overcoming challenges. Positive experiences instill greater confidence to meet future challenges, and are more likely to prevent development of negative

attitudes toward their illness. This is consistent with increasing evidence from the field of individual resilience indicating that, in order to adapt positively when faced with adversity, it is important to adopt a positive outlook and optimism (Masten & Monn, 2015). Similarly in the area of family resilience, having a positive outlook of life in general helped families adapt more successfully to the challenges of having a child with a chronic illness or disability (Bayat, 2007).

Organizational Patterns: Family Connectedness

Overall, young people's narratives expand upon what is known about family processes by providing descriptions on how greater cohesiveness buffered the effects of stress and reinforced the importance of family connectedness in facilitating young people's positive experiences of support within their families. Current findings complement other studies (Santos, Crespo, Silva, & Canavarro, 2012), which show that family activities and rituals play a significant role in increasing young people's perceptions of family cohesion and reducing family conflict. In turn, this has a positive effect on young people's psychosocial outcomes.

Family connectedness and support are interrelated: strong relationships within families were fundamental to the receipt and provision of support. Stronger connectedness provided young people more opportunities to seek support from family members. Consequently, this reinforced and strengthened family relationships. These findings add onto a growing body of evidence that greater family connectedness is associated with positive psychosocial outcomes among young people with chronic illnesses, such as greater quality of life and lower behavioral problems (McCusker et al., 2002; Swartz, 2010).

Interestingly, several young people from highly connected families did not actively seek support from family members and yet had relatively high self-esteem. There are several possible reasons for this. First, these young people had high self-confidence in managing demands and did not need additional support from their families. Second, they may be less comfortable in confiding or expressing their emotions. Several authors have stated that individuals from collectivistic and high-context cultures, such as Singapore, often exercise restraint in emotional expression (Ang, 2006). Third, the perceptions of available support in itself was a source of support. In other words, knowing that family members would be there for them (i.e., perception of available support) as opposed to confiding in family members (i.e., seeking and receiving emotional support). Therefore, it is insufficient

to focus on how families can provide support to young people, particularly, if young people are less inclined to confide their feelings.

Family Communication

In this study, we found that family communication was vital to young people's adaptation: processes that promoted resilience included collaborative problem-solving and shared decision-making. These processes, which were characterized by family members' openness to change and new solutions, having room for negotiation and compromise, allowed families to make decisions that considered family members' varying needs. These findings were similar to previous research among families of disabled children where the quality of family communication predicted higher levels of adaptation (Greeff & Nolting, 2013), and adolescents who report openness of communication with their parents had greater parent-child relationship satisfaction and higher self-concept (Sillars, Koerner, & Fitzpatrick, 2005). Together, these findings are consistent with Walsh's framework, which underscores the importance of communication processes in fostering resilience.

As mentioned, family communication plays a central role in facilitating exchange of information, problem-solving and decision-making processes (Rueter & Koerner, 2008). Differences between countries and ethnic groups were found in several domains of family functioning, including communication and affective expression (Chen & Kennedy, 2005; Keitner et al., 1990; Kennedy et al., 2004). Thus, there is a need to consider cultural influences when exploring how resilience in different societies manifest (Ungar, 2008), in particular, how individuals and their families engage with processes that promote resilience. During adolescence, the relational dimensions of parent-child communication, such as power and identity, becomes more prominent as established patterns of interaction are renegotiated in order to meet new demands for adolescent autonomy (Sillars et al., 2005). Therefore, it is essential to examine *who* were the decision-makers, and *how* decisions were made, and the way differences were resolved.

Cross-cultural research has shown that young people from Asian backgrounds tend to comply with parents and had lower levels in active coping when dealing with parent-related stress compared to those from European backgrounds (Persike & Seiffge-Krenke, 2016; Phinney, Kim-Jo, Osorio, & Vilhjálmsdóttir, 2005). It is likely that these differences stemmed from the greater value that young people from Asian backgrounds placed on family interdependence and respect for parental authority.

Additionally, such interaction patterns may not necessary result in poor psychosocial adaptation. For example, while disengagement from conflicts were negatively associated with poorer outcomes for Dutch adolescents (Branje, van Doorn, van der Valk, & Meeus, 2009), it was associated with positive adaptation Korean youths (Kim & Kim, 2008). Thus, family communication patterns that appear dysfunctional in one context may not be so in others, and it is important to consider the underlying values that guides family members' behaviors.

Strength and Limitations

Current findings provided a broad overview of family influences on young people's self-esteem. A strength of this study was young people's involvement in interviews rather than their parents, thus, providing a unique view on family processes. Consequently, these may be more valid as intervention targets for intervention with young people. Other family members may have different perspectives of their family processes. As each perspective is valued and valid in its own right, future research could also benefit from exploring views and experiences of young people's family members in order to gain a fuller understanding of the impact of epilepsy. In particular, it may be useful to utilize dyadic or group interviews to obtain information about the family by observing family interactions, dynamics and communications as they occur (Reczek, 2014). Other multi-method assessments, such as self-reports and ethnographic observation methods, could also be used to evaluate family interactions and resilience. Further research, which conducts in-depth exploration of family processes at various levels of psychosocial outcomes, should be conducted.

Implications for a Family Resilience-oriented Approach to Practice

Walsh's family resilience framework provides social workers and other practitioners with a multi-systemic perspective when working with young people in strengthening their capacities to manage multiple demands arising from a chronic medical condition. The findings of this study corroborate this framework, highlighting characteristics of key processes for resilience and its influence young people's experiences of living with epilepsy. Working in collaboration with young people and their families, practitioners could also apply the adaptational process model of family resilience when developing family-based interventions (Lietz, Julien-Chinn, Geiger, & Hayes Piel, 2016). This model, which was empirically derived from research conducted with families facing difficulties, reinforces the conceptualization of resilience as a process that develops over time. In particular, this model

highlights five phases within this process and the emergence of 10 family strengths (Lietz et al., 2016).

As existing literature suggests that most young people and families adapt successfully and do not necessarily have poorer outcomes compared to healthy peers (Herzer et al., 2010), this group could benefit from universal-level interventions that address their psychosocial needs. For instance, family and patients with different chronic medical conditions who received psychoeducation about family processes related with illnesses, reported improved quality of life (López-Larrosa, 2013). Based on the present study's findings, it would be useful to include topics addressing young people's autonomy, highlighting possible tensions between parent and child arising from conflicting demands. Additionally, differing expectations, lack of clarity of roles and responsibilities are likely to result in family conflict, poorer medical and psychosocial outcomes. Therefore, it is also essential to facilitate open communication where differing views are acknowledged and explored as it could potentially reduce socially imposed '*barriers to doing*', such as parental control and restriction. In addition, the findings also suggest that interventions should focus on ways to foster a stronger sense of connectedness between family members. Shared activities and rituals are likely to provide opportunities to enhance family cohesiveness, provide support and facilitate open communication between family members. As culture influences how young people and their families cope with epilepsy and its associated stressors, it is essential to bear in mind how culturally specific beliefs and values influence key processes that promote positive outcomes when planning interventions to support young people,

CONCLUSION

Young people's narratives highlighted the importance of strong family connectedness for the way it buffered effects of stress and facilitated adaptation. Strong bonds between family members were essential during times of stress as young people could turn to their families for support when needed. Family beliefs about normality, mastery and control also influenced how young people coped with epilepsy-related demands. Finally, beliefs and expectations not communicated between family members often resulted in disagreement or conflict. This unsolved conflict strained relationships, which in turn heightened young people's vulnerability for poorer adaptation. However, communication processes that facilitated collaborative problem-solving and shared decision-making were crucial in promoting resilience in young people living with epilepsy.

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